

Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences

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Title: Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences

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Abstract

Objective: To understand how parents view and experience their role as their child with a long-term **physical health** condition transitions to adulthood and adult healthcare services. **Methods:** Five databases were systematically searched for qualitative articles examining parents' views and experiences of their child's healthcare transition. Papers were quality assessed and thematically synthesised. **Results:** Thirty-two papers from six countries, spanning a 17-year period were included. Long-term conditions were diverse. Findings indicated that parents view their child's progression toward self-care as an incremental process which they seek to facilitate through up-skilling them in self-management practices. Parental perceptions of their child's readiness, wellness, competence and long-term condition impacted on the child's progression to healthcare autonomy. A lack of transitional healthcare and differences between paediatric and adult services served as barriers to effective transition. Parents were required to adjust their role, responsibilities and behaviour to support their child's growing independence. **Conclusion:** Parents **can** be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. To do so, they require clarification on their role and support from **service** providers. **Practice Implications:** Interventions are needed which address the transitional care needs of parents as well as young people.

Keywords: Parents; Child health; Long-term conditions; Transition; Qualitative research

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1. Introduction

Long-term physical health conditions (LTCs) affect significant and increasing numbers of adolescents in the UK [1]. Advances in treatment/technology mean that these young people are now more likely than ever to reach adulthood [2]. This will at some point, require them to assume a greater degree of independence and self-care than previously encountered [3], in addition to transferring from paediatric to adult services for ongoing healthcare [4]. The need for effective transitional care and the benefits this provides in terms of maintaining engagement with healthcare throughout the life course and improving health outcomes is well established [5]. However, transition cannot be conceptualised as young person-only phenomenon. Parents and adolescents together create the emotional environment necessary for the adolescent's adaptation to the demands of young adulthood [6,7]. Healthcare transition therefore also requires parents to adjust their care giving role, gradually relinquishing control of their child's LTC and supporting progression to young person autonomy [8,9]. Studies examining the role of family members during the transitional period [8,10,11] suggest parents face a range of new care challenges associated with their and their child's development, including adaptation to a changing role, allocation of treatment responsibilities and anxiety regarding their child's illness trajectory [12].

Despite recognition of the systemic nature of transition [7] and the effect of this developmental phase on shifting roles within family systems, previous reviews have focused on the perspectives of patients [13-15], transitional models [16,17] and healthcare practices [18,19]. Reviews have been carried out on the experience of parenting a child with a LTC [20] and on the effectiveness of interventions for parents of children and adolescents with chronic illness [21,22], however, these do not consider the experience of parenting a child with a chronic condition during their transition to adulthood and adult-services.

It is important to understand how parents experience their child's transition to adulthood because how parents manage and cope with their own change in roles and responsibilities will likely impact on both their child's transition to independent self-care as well as their own psychological well-being. Understanding the challenges that parents face, from their perspective, will further indicate support needs.

1.1 Aim & Objectives

This review aimed to collect and synthesise primary research relating to how parents understand and experience their role as their child with a LTC transitions to adulthood and adult healthcare services. The objectives were to: (a) understand how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services; (b) understand how parents experience their care-giving role in relation to their own well-being; (c) make recommendations regarding how healthcare providers can support parents during their child's transition.

2. Methods

The review adopted a systematic search methodology in accordance with PRISMA guidance [23] and followed the analytic procedure for 'thematic' synthesis [24].

2.1 Eligibility Criteria

To be included, papers had to report qualitative findings of primary research exploring parents' understanding and experiences of their role as their child with a LTC transitioned to adulthood and/or adult services. Parents included mothers, fathers and other primary care-givers (e.g. grandparents) of young people with long-term physical health conditions. In accordance with the WHO definition, an age range for young people of 10-24 years was stipulated. LTCs were defined as physical "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" [25]. This meant conditions that require on-going clinical care and self-management, for which medications are critical, and require follow-up at clinic. Examples include diabetes mellitus and cystic fibrosis. As the review focused on physical health, mental health conditions such as anxiety and depression were excluded, as were learning difficulties such as autism. Papers reporting studies with mixed samples (e.g. perspectives of young people, parents and professionals), were included if data pertaining to parents were reported separately or could be separated by the reviewers. Studies with wholly young person or professional samples were excluded. No limits were placed on the year of publication; only studies reported in English were included.

2.2 Systematic Search

Five electronic databases (Medline; CINAHL; EMBASE; PsycINFO; HMIC) were systematically searched to identify potentially eligible articles from inception until June 2015. Google Scholar was used to search for grey literature. A comprehensive search strategy was developed to include a combination of free text and index terms. Key search terms included parents; transition; hospital; chronic illness. The Boolean operator 'OR' was used to combine synonymous keywords, with 'AND' used to combine key concepts (figure 1). Articles identified by the electronic searches were downloaded into a reference management database and duplicates removed. Remaining citations were screened by the first author by title and abstract. Articles that clearly did not meet the inclusion criteria were excluded and all other possible relevant citations retrieved as full-text copies. All authors independently assessed the eligibility of retrieved full-text papers against the inclusion criteria. They then met to discuss their assessments. Uncertainties were discussed until consensus agreed. References of all included studies were hand-searched for additional articles which were assessed for inclusion in the same way.

2.3 Critical Appraisal of the Included Studies

Included papers were quality assessed using the Critical Appraisal Skills Program [26]. Quality assessment was carried out by the first author and a subset of papers checked by a second author. Studies of all quality were included with the quality of studies taken into consideration during data synthesis [27].

2.4 Data extraction

Studies were read before data were extracted and recorded. As well as basic study information, all text presented within the findings/results sections of each included article were extracted. This included data relating to key themes and concepts as expressed by the participants and by the

authors, using a pre-prepared form. Data were then imported into NVivo version 10 to support coding and quotation retrieval. The corresponding author of included studies was contacted to obtain further information where necessary.

2.5 Data synthesis

Data were synthesised thematically [24]. This method was selected as it provides a systematic and transparent approach which facilitates the production of rich and interpretive, yet data-driven themes, in order to broaden conceptual understandings of a particular phenomenon. Thematic synthesis has three stages: (1) coding of text; (2) development of 'descriptive themes'; and (3) generation of 'analytical themes'. While the development of descriptive themes remains 'close' to primary studies, analytical themes represent a stage of interpretation whereby the reviewers 'go beyond' primary studies, generating new interpretive constructs or explanations.

Inductive coding was carried out across the data set, independently by two authors according to its meaning and content [24]. Codes were then discussed with the third author and a coding frame agreed upon. This was subsequently applied to the findings of all included studies. Related codes were grouped together and labelled to form descriptive themes and a summary of each theme written. The final step of analysis, moving 'beyond' a thematic summary of included studies, was achieved by grouping and developing the descriptive themes generated from our inductive analysis to address the review objectives. This involved interpretative work by all authors, using the coded data set to understand how parents experience their care-giving role in relation to a) supporting their child's transition and b) their own well-being and c) to make recommendations for healthcare providers. During this process, new, analytical themes were generated which inferred implications for service provision from parents' descriptions of their lived experience. Here we present the analytic themes that were generated from our descriptive themes (see table X).

Trustworthiness was maintained using a number of strategies including keeping a clear and transparent audit trail, maintaining a reflexive approach, and discussing emerging understandings within a research team. We were aware that our position as health and social psychologists with training and experience in qualitative health services research would inevitably influence our interpretations. We therefore strived to remain open to unexpected discoveries by consciously reflecting on our knowledge and experience, critically appraising our individual and group level interpretations and discussing alternative explanations. It was through this process that we managed to agree on categories in which our various interpretations fit and that would contribute to the existing knowledge base in parenting and transitional care.

3. Results

3.1 Systematic search

1966 articles were retrieved for assessment against the inclusion criteria with 32 papers included in the review (figure 2). Papers presented qualitative data on parents' views and experiences of their child's healthcare transition in a variety of LTCs (asthma, arthritis, cancer, cystic fibrosis, congenital heart disease, cerebral palsy, diabetes, epilepsy, Marfan syndrome, sickle cell disease and spina bifida). Studies were conducted across six countries (Switzerland, UK, Canada, USA, Australia and

Netherlands) over a 17-year period (1997-2014) using a variety of qualitative data collection and analysis methods (table 1).

3.2 Quality appraisal

All studies were assessed as having a clear statement of aims, with an appropriate research design and methodology for addressing those aims. Only one paper discussed issues of reflexivity. This is important for considering whether and how the researcher/s might have impacted on the research outcomes. The majority of papers presented an appropriate recruitment strategy with data analysis that was judged to be sufficiently rigorous, providing a clear statement of findings and a valuable contribution to the research area (table 2).

3.3 Synthesis findings

Findings regarding parenting a child with a chronic illness as they transition into adulthood and adult services were generally similar across LTCs with some differences relating to the impact of the condition and treatment on the family's life and child's future. Findings that contributed to explaining parents' understanding and experience of their role during their child's healthcare transition were captured in eight themes, grouped to address the first two review objectives: views on transition; factors affecting child autonomy; preparation for healthcare transition; service provision; young person condition management; parents' experiences of their child's transition; parental transition; and impact of the LTC on the family (table 3). Each theme is briefly described with exemplar data extracts provided in table 4. Findings were then used to address the third objective, making recommendations for service providers, which is presented within the practice implications.

3.4 Understanding how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services

3.4.1 Views on transition

In most studies, independence-building, including transition toward self-management was regarded as "a positive social value" [28, p.997]; something parents viewed as important and were motivated to support their child to develop. Achieving healthcare independence was understood as an incremental and negotiated process of gradually transferring responsibility for self-care in accordance with other increases in responsibility unrelated to the child's health condition (e.g. staying away from home). Moving from childhood to adulthood was therefore characterised as having a number of different transitions (e.g. in healthcare systems, education). Healthcare transition was perceived as a process of mediated condition management; moving "forwards and backwards along the continuum" [10, p.2146] of young person and parental management, with parents stepping in to provide respite during times of stress or episodes of illness. The transition process was activated consciously following triggers such as parents being at work or child leaving home, or unconsciously in accordance with other "developmental considerations" [28, p.997].

3.4.2 Factors affecting child autonomy

Several factors influenced the child's autonomy acquisition in relation to the management of their LTC. These included parents' perceptions of their child's "developmental readiness" [29, p.419],

including beliefs about their child's "overall maturity and sense of responsibility" [30, p.9], their emotional stability and capacity to self-care. Reaching a point of readiness was considered individual to each child and depended on parental understanding of their child's competence and motivation to carry out self-management tasks such as medication administration, symptom monitoring and self-advocacy. This in turn was linked to parental trust in their child to be responsible for their condition, that is, how much they believed their child would adhere to their treatment regimen and not endanger themselves by engaging in risky behaviours. In addition, "stability of the young person's condition" [31, p.121] impacted on when transition to self-care was encouraged and how management tasks were shared. Generally, transition to self-care was seen to need to happen during a time of "perceived wellness" [10, p.2140].

3.4.3 Preparation for healthcare transition

Strategies used to prepare young people for assuming healthcare autonomy included parents encouraging and supporting their child to self-care, explaining and allowing their child to "experience the consequence of their actions" [30, p.10], modelling self-care behaviours, monitoring condition management and prompting treatment administration. Parents in several studies discussed actively teaching their children self-management skills including condition and treatment management, self-advocacy and "self-surveillance" of bodily symptoms [32, p.446]. They employed strategies for ensuring that their child was aware of and had access to their own medical history and practiced asking questions for consultations. Parents talked about offering "tangible assistance" [33, p.216] to their child in terms of filling prescriptions, making appointments and transporting the child to clinic. This was presented as the young person taking responsibility for self-management by instigating treatment adherence, but parents providing assistance where needed. Such a 'shared care' approach, where parents and young people worked in partnership to manage the health condition was described as a useful intermediary between parental and young person management.

3.4.4 Service provision

Concerns were raised about changes to service provision across paediatric- and adult-centred healthcare. In contrast to the adult sector, children's services were viewed as providing care that was tailored to the child's "unique and complex" needs [34, p.35] within a "warm, familiar, cosy and trusted" environment [35, p.826]. However, lack of preparation for transfer between services and a perceived lack of transitional care left parents experiencing a sense of "loss" [36, p.351] of support, resources and trusted relationships. This was regarded as a form of "abandonment and rejection" by paediatric professionals [37, p.362]. The absence of adequate transitional care further left parents to act as their child's transition co-ordinator, assuming responsibility for communicating between services, arranging orientation visits and clinic appointments at new hospital sites and organising the transfer of clinical notes. Service changes impacted on parents in terms of them experiencing a discontinuity of information from lone consulting and a loss of "their own support systems" [38, p.484]. Suggestions for improvement included better collaboration between paediatric and adult sectors; joint visits; starting the process of transition earlier; increased information provision, transition preparation and support groups.

3.4.5 Young Person Condition Management

Parents described varying degrees of involvement in the management of their child's condition, with mothers describing themselves as highly involved in managing their child's LTC on a day-to-day basis, taking responsibility for ensuring treatment adherence and administration [10, p.2138]. In contrast, fathers were found to take a more laissez-fair approach, assuming responsibility for ensuring the health of all family members rather than concentrating solely on the child's condition [39, p.767]. Many parents described conflicts arising from their protective parenting behaviours, for example, constant checking and questioning of their child's treatment adherence, lifestyle choices or engagement in potentially risky behaviours [40, p.13].

3.5 Understanding how parents experience their care-giving role in relation to their own well-being

3.5.1 Parents' experiences of their child's healthcare transition

Parents' experiences of their child's healthcare transition were characterised by feelings of "stress" [34, p.36], "turmoil" [37, p.361] and "fear" [37, p.362]. Stress and turmoil related to the families' detachment from paediatric services and "uncertainty" [41, p.345] regarding the move to adult care. A prominent source of anxiety was the tension between how much control parents should maintain over their child's condition/treatment and "how much responsibility" [30, p.4] they should handover to the young person. Parental reluctance to relinquish control was linked to their fear of "long-term health complications" [42, p.224] resulting from their child's engagement in risky behaviours including treatment non-adherence. "Letting go" [39, p.768] of control over their child's condition and treatment was found to be a "difficult process" [28, p.999] for parents, while maintaining control helped to manage their anxiety. However, this "need to stay involved in the child's health care" [43, p.330] delayed the onset of young person autonomy. Enlisting a network of "others outside the family" (e.g. friends, professionals at school/college) [42, p.226], who would help the young person adjust to their increasing independence and provide self-management support in the absence of parents also served to manage parental worry.

3.5.2 Parental transition

Included studies indicated that parents too were required to go through a process of transition, from parenting a child to parenting a young adult with a LTC. This transition presented "developmental challenges" [28, p.999] for parents themselves, demanding changes to their behaviour and adjustment to their role. An example was substituting "watching" [30, p.9] a young person administer treatment with "passive supervising" [10, p.2139]. In particular, parents described having to revise "their definition for successful [condition] management" [42, p.226] in line with what their child could achieve. In several studies parents expressed "ambiguity and uncertainty about what the new arrangements for care signified about their changed role" [28, p.997]; struggling to reconcile relinquishing control with providing support and guidance. Frequently this meant that parental support was not withdrawn completely, but that their previously held "managerial role" gave way to a new "consultant role" [44, p.190]. Most challenging was the role of "passive initiator" where parents initiated but had "no direct involvement or knowledge" [10, p.2140] of the child's condition management behaviours beyond reminding them.

3.5.3 Impact of LTC on family

Parents described how their child's LTC impacted on their family, including the impact of the condition on siblings, on parents' other roles, relationships and responsibilities and on the child's capacity to live a 'normal' life. Parents felt it was their duty to maintain "a positive attitude and outlook" for their child [42, p.226], redirecting focus away from the young person's limitations toward "possibilities of the future" [32, p.449]. Parents described their desire to maintain a sense of "normalcy" for their child [42, p.226]. This was achieved through treating the LTC as a "normal part of life" [45, p.12] and ensuring that the child lived as "normal" [44, p.190] a life as possible, despite their LTC. However, also expressed was a sense of "burden" [46, p.53] and burnout from parenting a child with a chronic illness, particularly those with life-limiting conditions.

4. Discussion and Conclusion

4.1 Discussion

This review thematically synthesised 32 papers from six countries reporting how parents understand and experience their role as their child with a LTC transitions into adulthood and adult healthcare services. Developing understanding of the parent perspective is essential for ensuring the provision of effective transitional healthcare. Although studies were diverse in terms of LTCs, they were comparable, enabling the development of overarching themes.

Findings revealed that parents generally view their child's progression towards self-care as a positive and incremental process which they seek to facilitate through up-skilling them in self-management practices. Parent perceptions of their child's readiness, wellness, competence and LTC impacted on child healthcare autonomy. A lack of transitional care, perceived differences between paediatric and adult services, and a loss of relationships, resources and support for parents and young people served as barriers to effective healthcare transition. Parents' experiences of their child's healthcare transition were characterised by ambiguity and uncertainty, leading to feelings of anxiety and distress. A strong source of anxiety related to fear of poor health outcomes from relinquishing control of the condition to the young person. In parallel with their adolescent child, parents were required to go through their own process of transition. This involved supporting the child's growing independence and adapting to a new role. Parents required support from healthcare providers to prepare for and manage their child's healthcare transition.

The core finding that parents have difficulties relinquishing control of their child's LTC for fear of poor health outcomes supports previous research on healthcare transition from the perspectives of young people and professionals [8,15,48]. It also aligns with research on emerging adulthood in a non-clinical population [49]. **In this review**, parental reluctance to relinquish control was related to perceived risk of shifting allocation of treatment responsibility to young people, and to inadequate professional co-ordination of the child's transfer across services [31]. While protective parenting practices served to promote child safety, they could also lead to reduced autonomy in early adulthood [15,50] stemming from increased parental attachment behaviour [51] and leading to emerging adults being averse to assuming adult responsibilities [52]. Young people have also expressed frustration at the over-involvement of parents post healthcare transition [53,54]. Parents therefore appear to be more concerned than their children about the adolescent's ability to be autonomous [35,55]. It is essential that parents understand the importance of supporting young people to develop the skills and confidence they need to effectively manage their own LTC

throughout and beyond transfer to adult care [56]. Healthcare professionals are ideally placed to work with parents to facilitate their and their child's growth and change.

Four domains of perceived parental support have been identified by young people and professionals throughout transfer to adult services. These include parents providing practical support, acting as 'trouble-shooters' in times of health-related crisis, working in partnership with young people to manage their condition and providing emotional protection [53]. Our findings support the need for parents to adjust their role to embrace that of 'partner'; sharing healthcare management with their child in a state of inter-dependence, as a bridge to full independence [57]. Shared care might include parents 'prompting' young people to administer treatment, fulfilling prescriptions and up-skilling them in self-care activities. This role is similar to that of a 'lay carer' as described by parents of adults with LTCs [58].

While parents are responsible for adapting their role to support their child during transition, healthcare providers are responsible for providing transitional care that addresses the needs of both parents and young people. Working in partnership with parents, as well as young people, will likely lead to a smoother and more effective transition for all. However, despite acknowledgement of the need for parent-targeted transition support [10,55,62] Allen et al [28] highlight that provision for parents is withdrawn at the time they need it most. Intervention studies remain limited. One paper reporting the development and evaluation of a peer support group for parents of young people with health conditions transitioning to adulthood [63] found that parents who attended the group gained new knowledge and became more future-oriented and active in their transition preparations. Further research is required to explore the effectiveness of interventions helping parents and young people define and respond appropriately to their shifting roles and responsibilities [8].

Lone consulting for young people remains controversial. Our findings suggest that exclusion from consultations is difficult for parents, particularly when they perceive their child is not coping well [12]. While professionals have shown empathy for parents' information needs, a belief that parents gradually lose their right to information about their young adult child's health is embedded in practice [53,59]. However, this issue is complex; while lone consulting is cited as a common goal in the transition process [9,60], research is clear on the protective nature of parental involvement in terms of disease control [8,11,61]. Thus tensions exist between guidance in the adolescent health literature emphasising the benefits of independent self-management and evidence that continued parental involvement leads to improved health outcomes. Recent best practice guidelines emphasise the need to regularly discuss with young people how they would like their parents to be involved throughout their transition [7]. Nevertheless, effectively balancing the young person's need for privacy/ confidentiality with their parents' need for sufficient information to provide self-management support requires further research [11].

Finally, our findings provide empirical support for the conceptualisation of healthcare transition as a multifaceted process involving partnership between numerous stakeholders (young people, parents, service providers) and systems (family, healthcare), as proposed within systemic and ecological theories [6,64-66] and in keeping with international policy studies suggesting the need for system-level transition strategies [67]. The finding that parental perceptions of the child's condition and abilities guide their willingness to transfer responsibility for condition management to young people further indicates utility of the Common Sense Self-Regulation model in which health behaviour is

theorised to be guided by cognitive and emotional illness perceptions [68,69]. Parents have been shown to hold representations of their child's condition and treatment which influence their behaviour regarding healthcare professional advice [70]. Parental self-efficacy beliefs about their capacity to change and effect change in their child's self-care behaviours is likely to be central to the success of interventions, as suggested by Social Cognitive Theory [71]. Theories of learning such as Social Development Theory [72] could also be applied, particularly the idea that learning self-management skills occurs during the interaction between individuals and more knowledgeable others (e.g. parents or professionals), and that the range of skill that can be developed with adult guidance exceeds that which can be attained alone.

A strength of this review is that by consolidating qualitative findings from diverse LTCs, we were able to identify a range of common experiences and needs of parents in dealing with a child's increasing autonomy acquisition, which may not otherwise have been identified had a disease specific approach been taken. These findings indicate the need for transitional care interventions which address the needs of parents as well as young people. That only small differences between conditions were found, suggests that the issues parents experience during their child's healthcare transition are generic. This aligns with existing research and suggests the utility of non-disease specific interventions [12,15,39,48,73,74]. A limitation of this review is that even though our definition of young people was broad, searches still identified papers discussing healthcare transition from the perspective of parents of children who fell outside of our specified age range [e.g. 62,75] and papers in which the parental perspective could not be distinguished from that of young people or professionals [e.g. 76,77]. These papers were subsequently excluded. Moreover, by focusing the review on physical health, mental health conditions and learning disabilities were excluded. Further research is needed to establish how transition may differ when young people have needs in these areas. Finally, despite a lack of (reported) reflexivity within included studies, which could be argued to impact on the trustworthiness of our review, that insights were derived from across (rather than within) 32 individual studies, indicates confidence in our findings.

4.2 Conclusion

Parents can be key facilitators of their child's healthcare transition, supporting and encouraging them to become experts in their own condition and care. To do so, parents require clarification on their role and support from service providers. Healthcare practitioners need to work in partnership with parents, in order to help them to facilitate their child's transition, and to maintain their own psychological wellbeing during a stage of parenting that is characterised by ambiguity, uncertainty and risk.

4.3 Practice Implications

4.3.1 Supporting parents to facilitate their child's transition

Findings suggest that parents can be key facilitators of their child's move toward healthcare independence. Rather than being excluded from the transition process, parents can be assets/resources for supporting the child's adaptation to self-care. Parents, as well as young people, therefore should be supported by health professionals and their needs addressed within transitional care interventions. Particular attention should be given to incorporating parents' helpful insights

about their child and their child's condition, as well as clarifying and supporting them in their changing role. Healthcare providers could work more effectively with parents to facilitate young person autonomy, by introducing families to the concept of "inter-dependency" and supporting them to practice a partnership approach which incrementally engages the young person in developmentally appropriate self-care. Strategies for supporting parents to facilitate their child's transition might include encouraging parents to identify or create opportunities to witness their child's capacity to be responsible for their healthcare; working with families to establish helpful condition management routines, systems and structures, and teaching parents to guide and supervise adolescents in their efforts to self-care; explaining the rationale for developmentally appropriate care (including lone consulting) and negotiating ways of feeding back to parents; teaching parents how to help their child to advocate for themselves (e.g. practising asking questions, modelling communication skills).

4.3.2 Supporting parents through their own transition

Findings further indicate that parents are required to go through their own transition process, from parenting a child to parenting a young adult with a LTC. Parental thoughts, feelings and behaviours regarding such change will inevitably impact on their acceptance of, and adaptation to a new role. Particularly anxious parents who overestimate the risks associated with young person autonomy for example, may be reluctant to relinquish control of their child's condition, leading to them practicing extreme levels of vigilance and protectiveness. This can be perceived as 'problematic' by professionals. However, these parents could be supported through their own transition by healthcare staff working with them to identify particularly anxiety provoking situations and teaching adaptive coping skills. Offering brief psychological interventions individually or in peer/parent support groups would convey sensitivity to the difficult and potentially distressing nature of transition for parents, as well as provide education and support. This would benefit parents who may be at risk of experiencing high levels of anxiety concerning "letting go" of established roles and responsibilities. For parents who are particularly distressed, referral to psychology services may be warranted.

4.3.3 Providing effective transitional care

Findings demonstrate that transitional care arrangements should be in place for parents and young people endeavouring to concurrently assume greater responsibility for self-care with transferring to an unfamiliar healthcare setting, regardless of their condition. While childhood chronic illnesses vary in clinical characteristics and treatment regimens, it is clear that transition issues are not unique to particular disease processes, but are shared among young people with LTCs and their parents. There may be scope therefore for generic transition programmes that address the needs of parent as well as young people and can be tailored to specific conditions. The current state of inadequate transitional care increases the need for a level of parental involvement which undermines the concept of healthcare transition. It further places significant burden on parents, increases perceived differences between paediatric and adult sectors and emphasises the impact of those changes on both parents (e.g. discontinuity of information) and young people (e.g. fewer resources).

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